Kleine-Levin Syndrome Foundation, Inc.

501(3)C NON-PROFIT ORGANIZATION

KLEINE LEVIN SYNDROME FOUNDATION

About Foundation

The KLS Foundation is a non-profit organization supporting the KLS patient community and scientific research. The KLS Foundation provides information and support to those diagnosed with KLS and their families. The Foundation exchanges information with patients and the medical community to help in the diagnosis and care of those affected by KLS, and supports research programs.

Goals of the foundation:

- Provide information and support to patients and families
- Increase physician awareness
- Organize KLS Conferences
- Fund medical research

Patient Registry

The KLS Foundation partnered with public health research firm Beneufit to create a patient registry that will accelerate our collective understanding and treatment of KLS. We intend the registry to maintain an accurate list of KLS patients, caregivers, and doctors for connecting the community to information, research opportunities, and one another.

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WHAT IS KLEINE-LEVIN SYNDROME?

Kleine-Levin Syndrome (KLS) is a rare neurological disorder, primarily characterized by recurrent episodes of hypersomnia (excessive sleep), and a mixture of cognitive and behavioral abnormalities. Hypersomnia can often last as much as 22 hours per day during an episode. A common cognitive characteristic is derealization, the sense of a dream-like state. Other symptoms may include changes in appetite, speech, memory loss, and behavioral changes, such as child-like language. Episodes may persist for days, weeks or even months. When an episode ends, most patients return to their normal state of functioning. However, some patients continue to experience some level of cognitive deficits in-between episodes, and in some cases, have long-term neurological impact. Affected individuals may go for a period of weeks, months or even years between episodes, and then symptoms may reappear with little to no warning. KLS episodes may continue to reoccur for many years, and most patients may stop having episodes all together.

WHO GETS KLS?

KLS is extremely rare, with an estimate of 1-2 cases per million people worldwide. KLS typically begins during adolescence, however, symptoms may arise earlier or later in life. Contrary to early reports, KLS presents itself in all races and ethnicities, and affects both males and females.

WHAT CAUSES KLS?

The cause of KLS is unknown. Current research suggests the following possibilities, individually and/or in combination:

- Autoimmune mechanisms
- Genetic predispositions
- Thalamus/Hypothalamus dysfunction
- Hypoperfusion in certain brain areas

Please visit the KLS Foundation website under the "What Causes KLS?" tab for more detailed information on this research.

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How To Donate

All donations go directly towards research funding and supporting for the KLS community. The KLS Foundation accepts donations from multiple methods, including paper check, debit/credit card, and of stock. Please visit the Foundaiton website under the "Donate!" tab for more information.

HOW IS KLS DIAGNOSED?

Diagnosing KLS can be very difficult because there are no symptoms that are entirely exclusive to KLS. Diagnosis is entirely observational through eliminating other possibilities, as there is no specific test for KLS. KLS belongs to the category of recurrent hypersomnia. It is imperative that other diseases and disorders are ruled out, such as bipolar disorder, autoimmune encephalitis, and PANDAS/PANS, that might be successfully treated. It is important to find a provider that is willing to look at a patient on a case-by-case basis, and familiarize themselves with current literature on KLS. Furthermore, diagnosis and a treatment plan does not require a neurologist or sleep specialist. General practitioners and other specialists may know about KLS. Ultimately, find a provider that is willing become familiar with KLS and support the patient in exploring treatment options.

HOW IS KLS TREATED?

There is no definitive treatment plan to reduce, prevent, or stop the impact/duration of KLS episodes. Various medications have been tried to relieve KLS episode symptoms, however, there are not consistent results from any one treatment/drug/therapy. The most common medications/therapies that have been attempted for relieving KLS symptoms include mood stabilizers, antiepileptics, stimulants, immune-modulators, antibiotics, and high doses of vitamin D3. A treatment may have benefit for one person, but not for another. It is important to have a supportive provider that is willing to “think outside the box" to properly manage a patient's care. Please visit the KLS Foundation website under "Treatment Options" for more detailed information about potential treatments.

STUDENTS, PARENTS, AND EMPLOYEES

KLS can pose challenges in academics and in employment. The Foundation wants patients to know that it is mandated by law for patients to have assistance. Students can receive accommodations through their school, and employees have rights through the Americans with Disabilities Act. More information can be found on the Foundation's website under the "Resources" tab.